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PAPER THREE

Does screening for physical and psychosocial symptoms vary between medical oncology treatment centres?

[INSERT LINKING INTRODUCTION HERE]

Does screening for physical and psychosocial symptoms vary between medical oncology treatment centres?

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ABSTRACT

Objective: To examine whether provider screening for physical and emotional symptoms, as reported by medical oncology outpatients, varies across medical oncology treatment centres.

Methods: A cross-sectional sample of 716 patients attending the outpatient medical oncology department of six public cancer treatment centres across five Australian states participated. Four patient-report survey items explored how often patients were specifically asked by clinical staff at the treatment centre about their (i) emotional distress (anxiety, distress, depression), (ii) pain, (iii) fatigue, and (iv) other physical symptoms (eg nausea, constipation). Asking at less than half of all appointments was classified as infrequent screening.

Results: No significant associations were found between treatment centre and symptom screening for emotional distress ($p = 0.65$), pain ($p = 0.21$), fatigue ($p = 0.95$), and other physical symptoms ($p = 0.40$). The proportion of patients who were regularly screened versus infrequently screened was significantly higher for physical symptoms than emotional symptoms ($p < 0.001$): 36% infrequently screened for emotional distress (range 33%, 45%), 15% infrequently screened for pain (range 9%, 21%), 16% infrequently screened for fatigue (range 15%, 19%), and 11% infrequently screened for other physical symptom (range 5%, 17%).

Conclusions: No significant variation in symptom screening was found across treatment centres. While the majority of patients received recommended care, treatment centres must continue to improve symptom screening rates, particularly for emotional distress. However, screening is only the first step, and must be accompanied by the offer of help and provision of help to relieve patient suffering.

BACKGROUND

Why evaluate the quality of patient-centred cancer care?

Patient-centred care is one the six central aims of quality of health care outlined by the Institute of Medicine (IOM) that should be pursued to facilitate improvements in quality of care. Patient-centredness is founded on the idea that quality health care not only aims to treat the cancer, but to relieve patient suffering and maintain quality of life[1]. Assessing the quality of patient-centred cancer care is essential to identifying barriers to the delivery of care and advocating for service improvement.

What aspects of patient-centred care should we evaluate?

The IOMs[1] recommendations related to relieving patients' physical discomfort and providing emotional support are able to be translated into measurable indicators of care, as best-practice has been articulated in the literature. According to clinical practice guidelines, patients' physical and emotional issues should be recognized and regularly monitored through symptom screening at all stages of the cancer journey to enable timely intervention[2-6]. For example, pain should be assessed at each encounter with the health service and before, during and after procedures. Fatigue should be 'routinely' assessed from point of diagnosis onward, including after completion of primary treatment. Distress should be assessed at 'regular intervals' and 'at times of change'. Symptom assessment may involve specifically asking patients about their symptoms during day-to-day encounters, or routine systematic screening of patients via a pen and paper or electronic surveys with the results fed back to providers to act upon during consultations [7]. Asking patients about their symptoms is important as it can't be assumed that providers are always aware of their patients' needs[8, 9], or that patients will actively inform clinicians when they are experiencing symptoms [10].

How should we evaluate delivery of physical and emotional symptom screening?

A variety of quality indicators[11-13] have been proposed to measure the delivery of patient-centred care. These measures of quality care vary in their content (ie, dimensions of patient-centred care;

process and outcomes assessed) and mode of assessment (eg. medical record abstraction, patient experience survey). Recently, international oncology groups have proposed a series of measurable indicators, appraised by searching patient medical records, to explore the quality of supportive care delivered in outpatient cancers. The indicators are intended to be examined across time and compared with other treatment centres as a strategy for improving care delivery [12, 14]. The current indicators relevant to physical and emotional symptom *screening* include documentation of the patient being assessed for the presence of pain and emotional distress within the 1 month after the initial visit. While use of medical record audit is appealing as it allows data to be drawn from a representative sample, it is not known whether management of symptoms is accurately documented in medical records.

Other methods of measuring quality of symptom screening (such as the existence of policies, clinician surveys, patient survey) also have distinct advantages and disadvantages that may affect measurement accuracy. For example, while assessing whether a hospital has guidelines for symptom screening can be undertaken at little cost, adherence to guidelines does not always occur[15]. Assessment of health care providers' perceptions of care delivery may be subject to social desirability reporting. Furthermore, providers' perceptions of health care may be discordant with those of their patients[16-18]. Patient self-report surveys may be a relatively costly and time consuming approach. However, given the personal nature of aspects of patient-centred care, the patient is in the best position to report whether they received the intended care and whether it helped to relieve their suffering or improved their quality of life[1, 19]. Consequently, it may be that patient perceptions are potentially a more sensitive and accurate measure of patient-centred care delivery[20, 21]. Such reasoning has led to the international growth of patient experience surveys[22, 23]. However, to our knowledge, no patient experience surveys have systematically explored variation in symptom *screening* across cancer treatment centres.

Why explore variation between cancer treatment centres?

Seminal work by Wennberg[24] identified unwarranted organizational variations in the delivery of a range of health care services that could not be explained by scientific knowledge. Variations were attributed to the ‘idiosyncracies’ of individual clinicians and institutions and availability of local hospital resources. Just as major variations in the technical aspects of medical practice continue to be identified across hospitals[25], so too may hospital-level variations occur in the delivery of patient-centred care. Understanding whether such hospital-level variations exist may help to pinpoint characteristics about the structure and process of care delivery at which we can intervene. For example, organisations that are more successful in recognising patient symptoms may have lower staff to patient ratios, implement policies and procedures for symptom management, or have available psychological services. The appeal of being able to change aspects of the treatment centre environment is that 1) the environment can simultaneously impact many patients and 2) patient outcomes may be affected without additional burden being placed on the patient via patient-focused interventions, such as patient prompt-lists to promote question asking[26].

Limited examination of variation across centres in patients’ perceptions of care for emotional and physical symptoms

A review of system-level variation in the delivery of patient-centred cancer care shows mixed outcomes. Shin et al [27] identified significant variation in pain management across 34 inpatient palliative care centres. Regional variation across the UK [22] and USA [23] in the delivery of patient-centred cancer care has been reported, including patient evaluation of pain management[22], physician communication, nursing care, and coordination of care[23]. Similarly, in a study of three cancer treatment centres, significant variation in patient satisfaction with nursing care was identified [28]. On the other hand, while Stolzmann et al[29] found variation in overall satisfaction with care across 128 medical centres, this was largely the result of differences between patient-level factors rather than hospital-level factors. Furthermore, while Kleeberg et al[30] found handling of symptoms and performance of medical staff varied substantially across cancer outpatient settings, further analysis revealed that high and low performing hospitals differed by patient characteristics including

age, cancer type and treatments received. Carey et al[31] did not find any variation in levels of patient anxiety and depression and perceptions of quality of care across four radiation oncology settings after adjusting for patient demographic and disease characteristics. To our knowledge, only one study has explored variation in *screening* of patient physical and emotional symptoms across cancer treatment centres[32]. This study employed medical record audit across 11 medical oncology practices in the USA and found that assessment of pain and distress significantly varied by practice site (14%-88% and 3%-45% not screened within one month of initial visit respectively) even after controlling for patient's age, gender and cancer type. The difference was attributed to clinic accreditation requirements and formalised screening processes.

Study aim

Given the potential limitations of medical record completeness for assessing aspects of patient-centred care, the primary aim of this study was to examine whether provider *screening* for physical and emotional symptoms, as reported by patients, varies across cancer treatment centres. Secondly, in a previous single-centre study using patient self-report data we established that fewer patients report being asked about their emotional symptoms compared to physical symptoms (Zucca et al. UER). Therefore, we also aimed to examine whether these findings remain consistent in a multi-centre sample.

METHODS

Sample:

Medical oncology treatment centres: Participants were recruited from six major medical oncology treatment centres across five states. Centres were eligible if they provided care for at least 400 new cancer patients per year.

Patients: Eligible patients within each of the medical oncology treatment centres had a confirmed cancer diagnosis of any cancer type, were attending an outpatient medical oncology unit for their second or subsequent appointment, were aged 18 years or older, were able to read and understand English, and were judged to be physically and mentally able to give informed consent and complete the survey.

Procedures

At each treatment centre, clinic staff identified potentially eligible patients from the daily clinic list. Potentially eligible patients were consecutively approached by trained research staff while waiting for their appointment in the clinic waiting room. Consenting patients completed a self-administered pen-and-paper baseline survey assessing patient, disease and treatment characteristics. To examine sample representativeness, the age and gender of non-consenters was obtained. A second survey assessing symptom management was mailed to consenting patients four weeks later. Non-responders received a reminder survey after three weeks, and a second reminder survey after a further three weeks. Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the ethics committee of the participating health services.

Measures

Physical and emotional symptom screening items:

A 4-item study-specific survey was developed to explore patient's perceptions of health provider screening behaviour. Physical and emotional symptoms which met the following criteria were prioritised: 1) they were prevalent for medical oncology patients and demonstrated gaps in care

delivery exist; 2) failure to deliver care will result in significant patient burden; 3) the issue is treatable or modifiable; and 4) the issue is important to patients. Corresponding items were drafted and iteratively reviewed by the research team, and then distributed to a sample of consumer advocates for additional qualitative feedback on item comprehension and relevance.

Four distinct symptom groups were selected as priority areas: (i) pain, (ii) fatigue, (iii) additional physical symptoms (eg nausea, constipation), from here on known as “other physical symptoms”, and (iv) emotional distress (anxiety, distress, or depression). For each symptom group, patients responded to one question asking how often a doctor or health care worker at the hospital or clinic from where they were recruited specifically asked if they were experiencing the symptom (ie, pain; fatigue; other physical symptoms, emotional distress) from their cancer or its treatment. Patients were asked to recollect across all appointments, since they first attended the clinic or hospital for their cancer care. Patients were instructed to select one option from the following six: 1) every appointment, 2) most appointments, 3) about half of my appointments, 4) less than half of my appointments, 5) never asked but I told the health care worker about this symptom, 6) never. Threshold scores were established using recommendations from clinical practice guidelines that emphasise the importance of screening at regular intervals and at times of change[2-4, 6]. Patients who responded that they were asked at either: ‘every appointment’, ‘most appointments’, or ‘about half of their appointments’ were categorised as having been regularly *screened*. Asking ‘at less than half of all appointments’ was judged as too infrequent. Therefore, those who responded ‘asked at less than half of appointments’ or ‘never’ were classified as *infrequently screened*. Patients who responded ‘never asked, but told the health care worker about the symptom’ were categorised as *patient volunteered information*.

Demographic and clinical items included age, sex, country of birth, marital status, education, cancer type, current remission status, time since diagnosis, number of clinic visits and reason for clinic visit was assessed at baseline.

Statistical analysis:

To examine sample representativeness, participant demographics were compared with those of eligible non-participants using chi-square analyses. Eligible non-participants were comprised of those who did not consent to the study and those who consented but did not complete a follow-up survey. For each of the four symptom groups, the proportion of patients 1) regularly *screened* by clinic staff or having *volunteered information* and 2) *infrequently screened* by clinic staff, was calculated for each treatment centre. To examine the association between screening and treatment centre, chi-square analyses was conducted for each of the four symptom groups. Finally, Cochran's Q-test was used to examine differences in symptom screening across the four symptoms comparing *screened* or *volunteered information* with *infrequently screened*. To explore the difference in screening across symptoms, a Cochran's Q-test was conducted on the mean screening rate across each centre.

Post-hoc power calculations were undertaken. Our sample was comprised of six treatment centres with sample sizes ranging from 84 to 244 patients per centre. Assuming a conservative 40% referent proportion, this number was sufficient to detect differences in the proportion of patients screened between at least two centres of at least 15% for each of the proportions of interest with a significance threshold of 5% and power ranging from 72% (smallest two centres) to 98% (largest two centres).

RESULTS:

Medical oncology treatment centres

Treatment centres were located in five out of the six Australian states. All centres were publically funded. While all centres were situated in urban areas, four centres were situated in major cities and two in inner regional areas. This distribution of centres approximately reflected the distribution of treatment centres across the participating Australian states (23% located in regional areas).

Patients

Across the six treatment centres, 1619 patients were approached between September 2012 and May 2014. A total of 282 patients were ineligible because it was their first clinic visit (n=103), were unable to read English (n=80), were previously approached about the study, or were not visiting for a medical oncology appointment (n=38), unable to complete survey independently (n=16), too sick (n=15), unconfirmed cancer diagnosis (n=4), or other unspecified (n=26). Of the 1337 eligible patients, 1137 (85%) consented to participate, and 944 (71%) returned a baseline survey. A total of 716 (63% response rate) returned a follow-up survey, 692 (97%) had complete data for one or more screening items, and 661 participants (92%) had complete data for all four screening items. Patient demographics and cancer-related characteristics are described in Table 1. Compared to all eligible participants, those who completed the follow-up survey were significantly less likely to be aged 18-34 years ($\chi^2(5) = 11.55$ p=0.04) and male ($\chi^2(1) = 6.579$, p=0.01).

Does symptom screening vary by cancer treatment centre?

Figure 1 presents the proportion of patients across each of the six treatment centres who were *infrequently screened*. Overall, 14.6% of patients were infrequently screened for pain (range 9.1%, 21%), 15.9% of patients were infrequently screened for fatigue (range 14.5%, 18.5%), 11.4% of patients were infrequently screened for other physical symptoms (range 5.1%, 16.9%), and 35.3% of patients were infrequently screened for emotional distress (range 30.4%, 44.8%). Univariate analysis revealed no significant association between treatment centre and *infrequent screening* for emotional

pain ($\chi^2(5) = 7.17$, $p = 0.21$), fatigue ($\chi^2(5) = 1.10$, $p = 0.95$), other physical symptoms ($\chi^2(5) = 5.12$, $p = 0.40$); and distress ($\chi^2(5) = 3.30$, $p = 0.65$). Consequently, no further testing was conducted to adjust for potential confounding.

Were fewer patients screened for their emotional symptoms compared to physical symptoms?

Across all treatment centres combined, the proportion of patients who were *infrequently screened* versus *regularly screened* or *patient volunteered information* was significantly different between the four symptom groups (Cochran's $\chi^2(3) = 249.54$, $p < 0.0001$) (Table 2). The majority of patients were screened at 'every appointment' or 'most appointments' for their pain (48%; 23% respectively), fatigue (40%; 27% respectively) and other physical symptoms (48%; 25% respectively), compared to less than half being regularly screened for emotional distress (30%; 17% respectively). A greater proportion of patients were never screened for emotional symptoms (22%) compared to physical symptoms (pain, 7%; fatigue, 5%; symptoms, 6%).

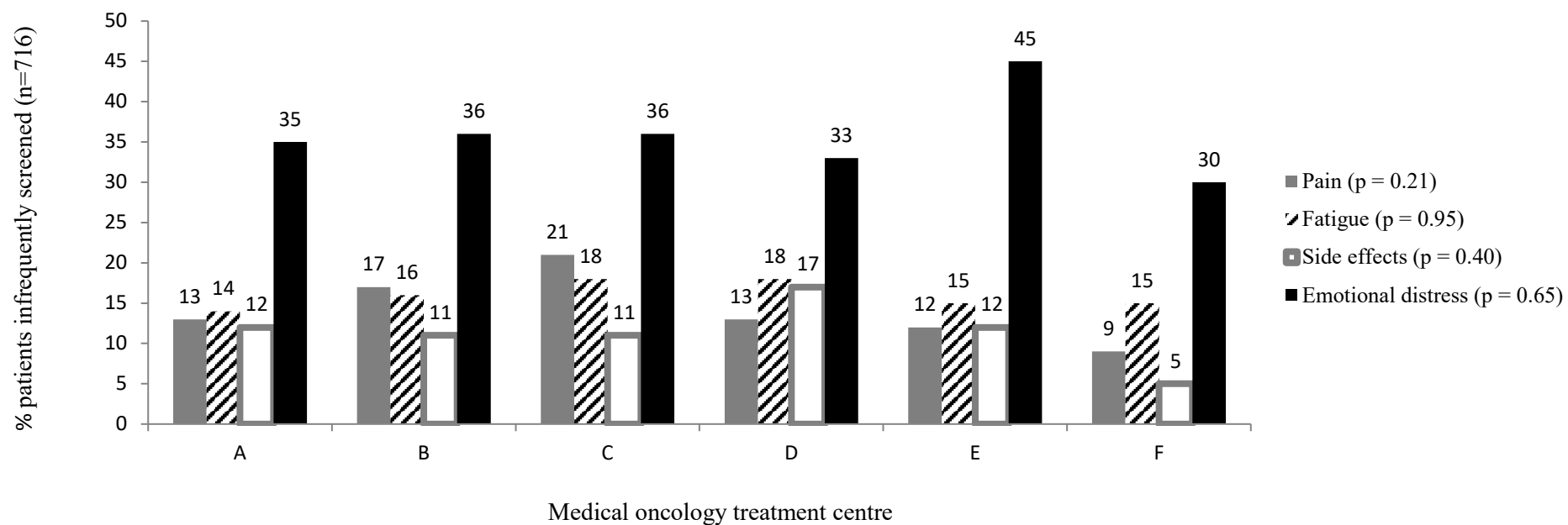


Figure 1. Proportion of patients infrequently screened for emotional distress and physical symptoms, by medical oncology treatment centre

Table 1 Patient demographics and cancer-related characteristics

	Sample
	N=716
	n (%)
Gender	N=716
Male	306 (43)
Female	410 (57)
Age at diagnosis (years)	N=689
Mean (SD)	61.8 years (SD=11.8)
18-34	16 (2)
35-44	42 (6)
45-54	128 (18)
55-64	210 (29)
65-74	207 (28)
75 or more	86 (12)
Marital status	N=695
Married or in a relationship	461 (66)
Single, divorced, widowed	236 (34)
Education	N=693
Primary school	41 (6)
High school	293 (42)
Trade or university	337 (49)
Other	22 (3)
Australian born	N=697

Yes	521 (75)
No	176 (25)
Cancer type	N=684
Breast	223 (33)
Colorectal	131 (19)
Lung	61 (9)
Upper gastrointestinal	58 (8)
Prostate	39 (6)
Other urogenital	39 (6)
Other	133 (19)
Remission status	N=582
In remission	134 (23)
Not in remission	292 (50)
Unknown	160 (27)
Months post-diagnosis	N=695
Less than 6 months	184 (26)
6-12 months	145 (21)
13-24 months	117 (17)
More than 24 months	249 (36)
Treatment ever received*	
Surgery	500 (72)
Chemotherapy	572 (83)
Radiotherapy	363 (56)
Hormone treatment	158 (24)
Biological therapies	84 (13)

Number of visits	N=676
Mean (SD)	19.7 visits (SD=18.5)
Less than 10 visits	226 (33)
10-19 visits	180 (27)
20-29 visits	103 (15)
30 or more visits	167 (25)
Reason for visit	N=685
Discuss treatment options	73 (11)
Receive treatment or check-up	370 (54)
Post-treatment follow-up	217 (32)
Other	25 (4)

Table 2: Frequency and percentage of patients by frequency of screening for each symptom

REGULARLY SCREENED or PATIENT VOLUNTEERED INFORMATION						INFREQUENTLY SCREENED	
		At every appointment	At most appointments	At about half of appointments	Never asked, but informed providers about symptom	At less than half of appointments	Never
	N	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Pain	678	327 (48.2%)	156 (23.0%)	61 (9.0%)	35 (5.2%)	50 (7.4%)	49 (7.2%)
Fatigue	681	269 (39.5%)	183 (26.9%)	64 (9.4%)	57 (8.4%)	69 (10.1%)	39 (5.7%)
Symptoms other than pain or fatigue	678	324 (47.8%)	166 (24.5%)	69 (10.2%)	42 (6.2%)	39 (5.8%)	38 (5.6%)
Anxiety, depression, distress	680	202 (29.7%)	116 (17.1%)	70 (10.3%)	52 (7.7%)	88 (12.9%)	152 (22.4%)
Cochran's $\chi^2(3)=249.54$, $p<0.0001$							

CONCLUSIONS

Symptom screening did not vary by cancer treatment centre

We found no significant variation among treatment centres in rates of screening for physical and emotional symptoms. To our knowledge, only one study has explored variation in *screening* of patient physical and emotional symptoms across cancer treatment centres [32]. The prior study, conducted by Jacobsen et al [32] in 11 hospitals in the USA, found significant variation in screening rates across centres. Findings indicated that between 14%-88% and 3%-45% not screened within one month of initial visit for emotional distress and pain respectively. In contrast, our study found more narrow rates of screening for emotional distress (30%-45% infrequently screened) and pain (9%-21% infrequently screened), compared to the USA (14%-88% and 3%-45% not screened within one month of initial visit respectively) indicative of greater uniformity in practices across centres. There were substantial differences with respect to our study and that of Jacobsen and colleagues which may account for the disparity in results.

Why our data differed from the Jacobsen et al data [32]

1. Health system differences: It is possible that fundamental differences in health service delivery may explain the differences. The Australian treatment centres included in this analysis are all publically funded, despite accounting for almost half (45%) of all Australia medical oncology treatment centres. The USA health care system is primarily a private enterprise, reflected in the 11 USA practice sites that demonstrated variation[32]. It can be beneficial for private enterprise is to strive to differentiate oneself from the crowd by applying innovations in products and processes [33, 34]. This differs to a government funded and administered health care system that seeks to standardise the delivery care [34]. Our findings may suggest that compared to a primarily privatised USA health system, publically provided Australian cancer care is delivered with greater uniformity.

2. Use of medical record versus patient self-report

Methodological differences in our study compared to the Jacobsen et al [32] may also explain the differences in centre variation in provider screening. Our study administered patient self-report surveys whereas the Jacobsen et al [32] study employed medical record audit undertaken by site-specific medical record abstractors. Despite growing interest in ensuring patient physical and emotional symptoms are documented [12, 35], it is unlikely that informal questioning of patients is documented on each occasion. It is possible that quality indicators assessed via medical record abstraction may reflect variation in documentation rather than actual delivery of care. Documentation of screening may systematically vary, potentially without any corresponding differences in care delivery. Consequently, patient-self report is considered the best method for measuring patient-centred care [1, 19]. The Commission on Cancer has recently recommended psychosocial distress screening should be offered, at a minimum, during a pivotal medical visit. Documentation of screening in the patient medical record is also required. These recommendations may mean that results of any future studies conducted in the USA may be subject to a reduction in variability in documentation.

Fewer patients were regularly asked about their emotional symptoms than physical symptoms

Fewer patients were regularly asked (at half of their appointments or more) about their emotional distress than their pain and other physical symptoms [32]. This finding was remarkably consistent across each of the six treatment centres, pointing towards homogeneity in care delivery despite very large distances of up to 4000 kilometres between the individual centres. This uniform approach to patient care, despite some variation in the type of patient within each centre. This remarkable lack of variation may be the result of educational training and certification of health providers by independent national bodies, and uniform values and expectations built from a tradition of government involvement in the organisation and administration of health care.

Providers may give higher priority to physical symptoms of cancer care than emotional symptoms. It could therefore be argued that a more conservative cut point (“ever” screened rather than “regularly” screened) should be applied to emotional symptom screening. Even when applying this cut point to the data via a post-hoc analysis, emotional symptoms (22% never screened) continue to be less frequently screened than physical symptoms (Cochran’s $\chi^2(3)=51.45$, $p<0.0001$). While patients are concerned about physical symptoms and side effects of their cancer and treatment[36], unmet needs related to psychological issues are consistently identified by patients across the cancer trajectory[37, 38].

Strengths and limitations

As a consequence of ethics processes being prohibitively expensive, no private hospitals were included in the sample despite accounting for approximately 45% of all Australia medical oncology treatment centres [39]. Exploring screening across a larger number of medical oncology treatment centres representing both the public and private sectors would improve the representativeness of the sample, and increase the likelihood of identifying between-centre variation. While this is the largest study of its type, generalisation of findings to all medical oncology clinics should be made with caution.

While patient self-report has been deemed an ideal measure of assessing patient centred care[1], recall may limit accuracy[19]. Furthermore, we chose to look at the functioning of the medical oncology unit as a whole, rather than assess individual providers. This approach provided a more generalised perspective of care delivered at the treatment centre, which was considered appropriate given the focus on multidisciplinary care in Australia. Future studies could explore a greater variety of symptoms.

Follow-up surveys assessing symptom screening were administered four weeks after the baseline survey. Patients had adequate opportunity to have received care at that hospital on several occasions

and to have been screened. However, administering items within a follow-up survey impacted on the response rate (63%) and our sample under-represented younger patients and males. Previously we did not identify any significant associations between sex and age and physical and emotional symptom screening (Zucca et al. under editorial review); suggesting we may not have incorrectly estimated symptom screening.

Implications and future research This study adds to the limited international knowledge about variation in patient centred care across treatment centres. Patients deserve to receive optimal care irrespective of whom they see, and which treatment centre they attend [1]. Importantly, uniformity of care is not desirable when it delivers less than optimal care. Our findings indicate that treatment centres in this study have an opportunity to improve their rates of symptom screening, particularly for emotional distress.

Patient-focused interventions to encourage active participation in health care, such as those to encourage patient question-asking, increase health literacy or empower patients to improve communication skills [26, 40-43] have had modest success. Giving responsibility to physically and emotionally vulnerable individuals to improve screening rates appears not only ineffective but also unreasonable. Responsibility for screening patients to establish their physical and psychosocial well-being surely rests with the clinical staff of treatment centres. To achieve this desirable outcome, there may be a need to critically examine existing treatment centre policies, provider beliefs and interpersonal skills. A system-based approach, such as distress screening[44], will be required where common barriers such as forgetting to ask, lack of role definition about addressing psychosocial or information needs, referral pathways, and perceived lack of time are overcome[45, 46]. Before widespread adoption of any of these approaches occurs there is a need to rigorously test whether such interventions have an impact on patient outcomes[44].

Finally, there is also a need to ensure that improving care delivery in treatment centres is guided by accurate and credible measurement. Without this it will be difficult to persuade providers,

administrators and health care systems to undertake quality improvement initiatives. Future research should triangulate quality indicators abstracted from medical records with equivalent patient self-report data (and vice versa)[35]. Such an approach would help to ensure our data are best positioned to inform care delivery.

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